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ABSTRACT

While many health care delivery systems are criticized for the dehumanizing way they treat patients, hospice care presents a refreshing alternative to health care for the terminally ill. Patients appropriate for hospice care are those with six months or less to live. Interpersonal communication education is an important component of hospice care training programs; before staff members or volunteers may work with hospice families, they must complete 30 hours of supervised training in various aspects of the communication process. A high degree of uncertainty is present in the situation for both the family and team members, but most research indicates that the optimum situation for dying persons and their families occurs when the impending death is faced openly--the "open awareness" context allows persons to review and make sense out of their relationships, to handle the business aspects of dying as a team--putting wills and financial affairs in order--and to share grief with the persons who are best able to understand it. Hospice workers receive extensive training in the following interpersonal communication skills: (1) owning feelings, (2) accepting feelings, (3) sharing feelings when appropriate, (4) active listening to content and relational messages, (5) responding to content and relational messages, and (6) some conflict resolution strategies. They are taught how to describe the family system and how to intervene to provide more satisfying communication exchanges. (A short bibliography is included.) (NKA)

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INTERPERSONAL COMMUNICATION INSTRUCTION IN THE NON-TRADITIONAL CONTEXT: TEACHING COMMUNICATION STRATEGIES IN A HOSPICE SETTING

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> I have a hard time falling asleep. Tomorrow is the day! I will meet my first patient, a dying woman. What kind of person is she? Does she know she is dying? How will it be for me to be face to face with her?
>
> Yes, I had my Hospice training. We talked and read about death and discussed dying back and forth in the past months. But that was the theoretical stuff, now comes the real thing. How will it be? I awaken several times duing the night, tossing and turning.
>
> Eva Balazs [1984]

Unlike most health care programs, hospice care focuses upon the quality of life that remains for the dying person. By describing the unit of care as the dying person and his/her family or support system, hospices have a distinct and important place in health care delivery. When most health care delivery systems are criticized for the de-humanizing way they treat patients and most insurance reminbursement plans determine how long one can stay in an acute care hospital and what treatments are required, a hospice presents a refreshing alternative to the health care for the terminally ill.

Besides treating both dying persons and their families, hospice care has other unique attributes. Care is palliative, rather than curative. The caregivers use a team approach when working with the patients and families. The team is comprised of medical and non-medical professionals and volunteers. Emphasis in the care plan

is given to pain control. The team addresses psycho-social, legal, economic, and spiritual aspects of the patients' lives along with medical aspects. Dying persons, their families and their caregivers participate in anticipatory grief before death occurs. Hospice nurses teach families how to care for their dying members at home and provide 24 hour on-call-services for those families. Physicians make home calls to visit dying patients. The period prior to a patient's death is viewed as a period of developmental growth for the patient and family. Hospice care includes bereavement services for the survivors.

Patients appropriate for hospice care are those with an identified terminal illness in the final stages and with a prognosis of living approximately six months or less. The care plan that is established with the patient's primary care physician includes symptom evaluation and control, pain evaluation and control, management of medications, general health teaching, teaching the patient's care, anticipatory guidance for patient and family in the progression of the disease, availability of community resources for the family, continuous evaluation of the patient's and family members' emotional states, provision of continuity of care among team members through weekly case conferencing involving all hospice disciplines.

The purpose of the bereavement program of the hospice is aiding members of the community in the reconstruction of their lives and reinvestment in living after loss through death of a family member or friend. The goals consist of educating persons about the grief process, supporting them through their bereavement period, and guiding them through the grief process by providing appropriate written and verbal tools as an aid and by referring them to other community resources that my be helpful.

The purpose of this paper is to demonstrate how interpersonal communication education is integrated into the training programs for hospice staff members and volunteers. The hospice described in this paper is a community-based hospice which is supported by United Way allocations, memorial donations, grants and fund raising events. This community-based hospice offers free services to dying patients and their families in their homes. Before staff members or volunteers may work with hospice families, they must complete 30 hours of training, a field assignment that is supervised, and an introduction into the team. While working with patients, the individual attends weekly staffing sessions which treat all aspects of dying persons and their families.

The hospice training program is divided between the affective and cognitive domains and uses many modes of instruction. Typically the training program covers the following topic areas:

a. Death and Dying and The Hospice Concept

b. Communication Skills in Hospice Care

c. Dying Persons and the Family System

d. Medical Aspects of Dying: Symptom and Pain Control

e. The Team Concept: The Roles of the Primary Care Physician, the Nurse, the Medical Director, the Nuitritionist, the Therapists, the Attorney, the Funeral Director, the Minister, Rabbi or Priest, the volunteer, etc.

f. Children and Death

g. How the Volunteer Helps

h. Anticipatory Grief, Bereavement and Loss

i. Stress Management for Hospice Team Members and Families.

j. Relationship Completion

Because the length of the training program, I will address the communication environment of the families with dying members that is presented in the training classes and point out which communication skills are emphasized. Training strategies will then be discussed.

Both family members and hospice workers are characterized by high uncertainty. Often the nature of the disease, the lack of familiarity with the health care system and its language, the inability to construe life without the family member, and the

immediate changes in the daily life routines in the family because of the patient's illness all contribute to the family's uncertainty. Likewise the hospice workers who enter the family system are uncertain of how the system operates, and how they will respond to the system and its rules.

What can be said about the dying process and to whom becomes an essential consideration for both family members and hospice workers. Glaser and Straus's [1965] awareness contexts are reveiwed with the hospice workers. In the closed awareness context, the patient has no allies to give the information about impending death. The family usually establishes the ground rule that the patient would be too upset to know about the death. This decision by the family creates elaborate rules about who can talk about the death and when. The relational messages that the patient picks up verbally and nonverbally are elimination from the intimate exchanges of the family. The closed awareness context eliminates the anticipatory grief process in which both the dying person and the family can be supportive to each other in preparing for the loss.

In the suspicion awareness context, the clues about death become too strong to overlook. Patients try to find out about how sick they are, but are not allowed into the discourse about their own deaths. Family members and health care personnel rationalize that the dying persons would give up hope if they were told the true nature of the their illnesses. The suspicion awareness context also

eliminates open, mutual preparation for the loss, but adds another dimension. Dying persons recognize that they are eliminated from the intimate levels of exchange that other family members still share.

The mutual pretense context creates a game where all parties agree to a set of implicit rules based on keeping the dying circumstances from being explicit. Family members guess, often incorrectly, how much the dying person knows. With the dying person's and the family's attempts to protect each other, they often reduce the amount of support, preparation and care that would be possible in the open awareness context.

Most research indicates that the optimum situation for dying persons and their families occurs when dying persons and others in the environment know about the impending death and can relate to each other through this knolwedge [Kalish & Reynolds, 1976]. The open awareness context allows persons to review and make sense out of their relationships, to handle the business aspects of dying as a team (wills, decisions about funerals, putting into order the fininacial aspects of the family, determining the care of families members who will survive, and sharing grief with the persons who are best able to understand it.) However in this context, it is important to know that the family and dying patient may move back and forth between awareness and non awareness. They weave in and of certainty.

There are differences between the relationships one enters as a hospice worker and other relationships. When a hospice worker is introduced to the family, the normal rules of low intimate self disclosure are violated. By wearing the hospice badge, hospice workers signal to the family that it is all right to talk about the family member's impending death and what that means to the family. Frequently hospice workers who fear the uncertainty of making the first call to the family, remark that after brief introductions, they have reached a deep level of self disclosure. Where family friends are hesitant to talk about the family's needs and fears, hospice workers are trained to do so. They are credible almost immediately as persons who will talk about the most important issues of the family which family members would never consider sharing with their friends and aquaintances.

Hospice workers enter relationships with dying persons knowing that the relationship is going to be completed in a short period of time. This understanding allows the participants to reach more quickly for depth in the relationship.

Communicating with dying persons entails sharing at intense emotional levels. Kubler-Ross [1969] presented a linear progression of emotional responses of dying persons: denial, anger, bargaining, depression and acceptance. Dying persons and their families experience these stages, often they experience these stages at

different times which adds further complication to the communication exchanges. Shneidman [1980] states that dying persons and those close to them experience a "hive" of emotions. They don't go through stages, rather they waver between denial and acceptance, disbelief and hope, rage and equanimity.

Wiseman [1972] developed the concept of an appropriate death. Many attributes of an appropriate death are communication attributes: recognition and resolution of any conflicts before death, yielding control to others in whom the dying person has confidence, and protection of the dying person's autonomy as a decision maker. How the relaionship with the dying person is concluded will have long range effects upon the survivors and short range effects upon the dying person and the survivors.

Hospice workers get extensive training in the following interpersonal communication skills: Owning feelings, accepting feelings, sharing feelings when appropriate, active listening to content and relational messages, responding to content and relational messages, and some conflict resolution strategies. They are taught how to describe the family system, recognize effective and ineffective communication exchanges in the family setting and how to make interventions to provide more satisfying communication exchanges. The communication skills training is practiced in the classroom setting, and during the training period the

trainees are expected to keep journals in which they use the skills.

After the training class is completed, the weekly staffing for hospice workers is used to continue the practice of the communication skills. Each non professional staff member or volunteer is supervised by a professional who reinforces the use of the communication skills that are taught during the training.

Some of the strategies used in the communication training are listed below:

a. Role Play - interactions with dying persons, their families and hospice workers are described and trainees assume the roles. After the roles are inacted the small groups discuss what strategies were effective and ineffective.

b. Discussion of Here and Now Feelings - because of the nature of the content of the class, trainers share their own feelings about what is being discussed and assist others to the do the same when it is appropriate.

c. Drawing Family Systems and Describing Them - in order to look at family patterns of interaction, the trainees start with the ones with which they are more familiar, their own.

d. Drawing and Discussing Life Lines - trainees are

asked to describe the past and future of their own lives in order to understand the special context of the dying person. They are asked to consider the ramifications of moving the end point of their life line much closer to the present day.

e. Developing a Relational Will or Writing their Obituary - trainees begin to understand what in their lives are significant to them and how they want those significiant aspects to be remembered by others.

f. Life Review - in order to make sense out of the lives of dying persons during the days preceding their death, trainees are taught to use significant things to help the dying person review their lives, i.e. photo albums, vacations they took, jobs they held, family members who have made an impression on them, historical events through which they lived, or places where they lived.

g. Developing a List of all Aspects of the "Business" of Dying - trainees consider what information the dying person and the families might discuss that would help the dying person maintain individual autonomy and help the survivors who are faced with many decisions immediately before and after the death.

h. Discussing Biographies, Autobiographies, Novels, Plays, Poetry, Other Creative Arts that Treat Aspects of Death, Dying and Survival

11.

i. Considering All Aspects of Relational Completion - good byes, gift giving, relational review, and recognition.

j. Cultural Perspectives on Family Interactions and the Treatment of Dying Persons

Hospice trainess leave the class with many alternatives for communicating. Instead of leaving with prescriptions about what to do and what not to do, they are encouraged to listen well and then respond. If their response is inappropriate, they have learned many other skills to try out in the situation. Communication in the family, with the dying person and with the hospice team members is a continual agenda item at the weekly staffing. One of the hospice volunteers who had received the training class a few years ago, accosted me at the grocery store one day. He mentioned that he is grateful that he learned the communication skills during the class. His final words to me were: "No matter whether the stressful situation is happening at home, the office and with a hospice family, I have learned to listen and then paraphrase. When I don't, I get into trouble." Hospice workers frequently mention how the hospice experience enriches their lives. Those of us who teach interpersonal communication skills in an applied setting are enriched also.

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